

Clearly endowed by God, the power of Mother Teresa's heart transcends the power of the world.

STATEMENT ON ALS RESEARCH, TREATMENT AND ASSISTANCE ACT

HON. WALTER H. CAPPS

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

Monday, June 23, 1997

Mr. CAPPS. Mr. Speaker, together with my colleague BEN GILMAN, I am today introducing the Amyotrophic Lateral Sclerosis [ALS] Research, Treatment and Assistance Act of 1997. This bill is designated to assist individuals with ALS, encourage advances in treatment, and accelerate research support at NIH.

The terrible nature of ALS was recently brought home to me through a very close friend of mine, Tom Rogers, who is suffering from this disease. Tom has been an able and compelling legislator, and a leader in the environmental movement in Santa Barbara County. His struggle with this disease has been heroic and an inspiration to all who know him. During my campaign for Congress, Tom gave me his running shoes which he said he no longer had any use for due to the debilitating aspects of ALS. I wore those shoes through the months leading up to my election. To this day, that gesture of friendship and support has continued to be a source of inspiration for me.

While most of us know of the famed baseball star for which this disease is named, many of us are unaware of the tragic consequences of Lou Gehrig's Disease. First diagnosed over 130 years ago, ALS is a progressive, fatal neuromuscular disease afflicting 25,000 to 30,000 individuals in the United States today. Approximately 5,000 new cases are reported every year.

Victims of the disease are struck by a creeping paralysis that eventually leaves them unable to eat or even breathe. There is no cure for ALS and researchers are just now beginning to understand what kills the nerve cells in the brain and spinal cord that lead to the disease's destructive effects. ALS usually strikes people in their 50's or later and life expectancy is a mere 3 to 5 years.

My bipartisan bill would waive the 24-month waiting period for Medicare eligibility on the basis of disability for ALS patients. This is only fair since life expectancy following diagnosis is often shorter than the waiting period and most ALS patients will have paid into the Social Security system well before the onset of ALS.

Disabled people under age 65 are eligible for Social Security Disability Insurance and Medicare benefits. However, there is a 5-month waiting period from the onset of the disability until SSDI benefits are granted and then a further 24-month waiting period for Medicare eligibility. Unfortunately, since ALS patients' life expectancy is only 36 to 60 months, the 29-month waiting period leave them little time to participate in Medicare. This is unfair as most ALS patients have had productive working lives prior to onset of the disease and an estimated 17,000 of them are not age-eligible for Medicare. The cost of assisted living care and various effects of the disease can leave many patients' families financially drained. Victims of end stage renal disease, who experi-

ence a similar life expectancy as ALS patients, are granted this waiver.

The Capps-Gilman bill would provide Medicare coverage for outpatient drugs and therapies for ALS. This provision would ensure patient access to such treatments and help spur the development of new treatments for ALS. Currently, Medicare part B provides drug coverage for five other afflictions: oral cancer, clotting factors, immuno suppressives, osteoporosis, and hemophilia.

Finally, this legislation would double Federal funding of research into the cause, treatment, and cure of ALS. NIH-sponsored ALS research totaled only \$12 million in fiscal year 1996. Clearly, more must be done. Recent advances in ALS research have produced promising leads, many related to shared disease processes that appear to operate in many neurodegenerative diseases. Increased research funding for NIH can speed up work on these promising leads.

Mr. Speaker, I urge the support of my colleagues for this critically important legislation.

A TRIBUTE TO U.S. WEATHER BUREAU'S NORTH ATLANTIC PATROL

HON. SUE W. KELLY

OF NEW YORK

IN THE HOUSE OF REPRESENTATIVES

Monday, June 23, 1997

Mrs. KELLY. Mr. Speaker, my fellow colleagues: I would like to call your attention to a great service rendered to this country by the men who served as civilian weather observers with the U.S. Weather Bureau's North Atlantic Patrol during the Second World War. These men significantly impacted the success of D-day, and many other battles of World War II, and yet, they have never been given the public appreciation they so richly deserve.

One of my constituents, Mr. Ray McCool, told me of these men, serving in the North Atlantic Weather Patrol aboard Coast Guard vessels, who obtained and transmitted essential weather data to Washington, DC. As a result, they made possible the preparation of weather maps used throughout the war. In fact, their long-range forecasts provided vital information needed to plan the D-day invasion. Their knowledge and talents made an enormous difference in the success of the overall mission and ultimately in an Allied victory.

Their service was not without danger and sacrifice. Under the Geneva Convention Articles of War, the rules for treating military prisoners did not apply to civilians. Therefore capture by the enemy most likely meant being treated as a spy and shot. To prevent this, they were outfitted in Coast Guard uniforms, carried as chief petty officers and enlisted into the service as "U.S. Coast Guard Temporary Reserves."

If capture by the enemy wasn't worry enough, they had the high seas and enemy ships to face. A typical mission took these men out to sea for 4 to 6 weeks at a time where they dealt with hurricanes and attacks from depth charges, U-boats, and German submarines.

To date, the United States have never fully recognized the invaluable job these civilian weather observers performed.

Today, let the record show we salute these unsung heroes and acknowledge their service

to our Nation. Further, in order to show our proper recognition, I am recommending that each local veteran's office present a U.S. flag to the family of a deceased member of this elite ensemble of men. In the face of danger and against the odds, these men stood tall and answered our country's call to freedom, and for that the United States of America is forever grateful.

PERSONAL EXPLANATION

HON. NICK J. RAHALL II

OF WEST VIRGINIA

IN THE HOUSE OF REPRESENTATIVES

Monday, June 23, 1997

Mr. RAHALL. Mr. Speaker, I was unable to be present for rollcall Nos. 224, 223, 222, and 221 on June 20, 1997. Had I been present and voting, I would have noted in favor of these four amendments to the Defense authorization bill, H.R. 1119.

OPEN LETTER OF SENATOR NANCY KASSEBAUM BAKER AND VICE PRESIDENT WALTER MONDALE TO THE PRESIDENT AND MEMBERS OF CONGRESS CONCERNING BIPARTISAN CAMPAIGN REFORM

HON. MARTIN T. MEEHAN

OF MASSACHUSETTS

IN THE HOUSE OF REPRESENTATIVES

Monday, June 23, 1997

Mr. MEEHAN. Mr. Speaker, last week two of America's most respected and distinguished senior statespeople, Senator Nancy Kassebaum Baker and Vice President Walter Mondale, visited with several bipartisan reform leaders on Capitol Hill, including myself and several of my fellow cosponsors of the Bipartisan Campaign Reform Act of 1997. The purpose of their visit was to discuss an open letter they wrote to the President and to Members of Congress on the topic of campaign reform. For my colleague Representative CHRISTOPHER SHAYS of Connecticut and myself, I enter Senator Kassebaum Baker and Vice President Mondale's letter into the CONGRESSIONAL RECORD.

AN OPEN LETTER TO THE PRESIDENT AND THE CONGRESS OF THE UNITED STATES FROM NANCY KASSEBAUM BAKER AND WALTER F. MONDALE,

Washington, DC, June 18, 1997.

DEAR MR. PRESIDENT AND MEMBERS OF CONGRESS: In March, the President asked that we help in the cause of campaign finance reform. Since then we have observed closely the national discussion of this issue, which we believe is central to the well-being of American democracy. We would now like to report about our initial recommendations, with a plea, in the best interests of our political process, that the Executive and Legislative Branches commit themselves to a course of urgent debate leading to early and meaningful action.

One of us is a Republican. The other is a Democrat. We are inspired by the bipartisan efforts of Senators John McCain and Russell Feingold, and Representatives Christopher Shays and Martin Meehan, to achieve campaign finance reform. The bipartisan effort of new members of the House, led by Representatives Asa Hutchinson and Thomas